PCAST Report Workgroup
Draft Transcript
January 27, 2011

Presentation

Judy Sparrow – Office of the National Coordinator – Executive Director
Good morning, everybody, and welcome to the Policy Committee's PCAST Workgroup. Just a reminder this is a Federal Advisory Committee, so there will be opportunity at the end of the call for the public to make comment and also a reminder for Workgroup members to please identify yourselves when speaking.

Let me do a quick roll call. Paul Egerman?

Paul Egerman – Software Entrepreneur
Yes.

Judy Sparrow – Office of the National Coordinator – Executive Director
William Stead? I know he's dialing in. Steve Ondra?

Stephen Ondra – NeHC – Senior Policy Advisor
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
John Halamka will be dialing in a little late. Dixie Baker?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I'm here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Wes Rishel?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Stan Huff? Leslie Harris?

Leslie Harris – Center for Democracy & Technology – President & CEO
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Robert Kahn? Gary Marchionini?

Gary Marchionini – University of North Carolina – Dean & Professor
I'm here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Richard Platt?

Richard Platt – Harvard Medical School – Professor & Chair
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Carl Gunter? Hunt Blair?

Hunt Blair – OVHA – Deputy Director
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Tim Elwell?

Tim Elwell – Misys Open Source Solutions – Vice President
Yes. I'm here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Steve Stack?

Steven Stack – St. Joseph Hospital East – Chair, ER Dept
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Mark Rothstein?

Mark Rothstein – University of Louisville – Chair of Law and Medicine
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Eileen Twiggs?

Eileen Twiggs – Planned Parenthood Federation of America – Director
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Jonathon Perlin?

Jonathan Perlin – Hospital Corporation of America – CMO & President
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Doug Fridsma?

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
Here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Farzad is going to be dialing in a little late and I'm not sure if Jodi's going to make the call. Did I leave anybody off?

Carl Gunter – University of Illinois – Professor
Carl Gunter is here.

Judy Sparrow – Office of the National Coordinator – Executive Director
Oh, Carl. Thank you. All right. With that I'll turn it over to Paul Egerman.

Paul Egerman – Software Entrepreneur
Good morning. This is Paul Egerman and I want to welcome you to our Workgroup conference call that is part of the HIT Policy Committee that is going to be reviewing the PCAST Report and helping ONC determine what the impact of the Report is and what their options are. This conference call is a public call and so we realize there are members of the public listening over the 800 number or perhaps over the Internet; so to the members of the public, I want to particularly welcome you, say good morning and there will be time at the end of the call for public comment. You will see in this call that we take the public comments very seriously because a major part of what we will be accomplishing today will be to review the public comments that have been received through the Internet as a result of the publication in the Federal Register of the series of questions that ONC asked.

What you see on your screen is a list of the Workgroup members. We're very pleased to have such a dedicated group of people involved with this very important project. Also what you see on your screen is just to remind everybody what our charge is. What we are doing is we are basically assisting ONC with the process of synthesizing and analyzing the public comments and input to the PCAST Report, so that will be one thing that we'll be starting to work on today. Then we'll discuss the implications of the report and its specific recommendations to ONC on current ONC strategies and the reason specific recommendations to ONC is put in red is that's really how we track changes. That was changed from our very first charge. We wanted to make it clear that we're not addressing, for example, the things in the PCAST Report related to CMS. That's outside of our scope. Then the last two bullets are assessing the feasibility impact of the Report on ONC programs and elaborate on how the recommendations could be integrated into the ONC strategic framework. So that's all very important work and it's work that's being done on a very aggressive time frame.

You see the meeting dates listed here. In the middle it says, "February 15, 16, 17 – one of these dates for a hearing." We have solidified those dates. It will be February 15th and February 16th. The schedule is created such that we are intending to complete our work and have sort of a report in response to our charge by mid-April; it's actually April 13th is the date of the Policy Committee meeting that we hope to be presenting a final report. So that's a very aggressive schedule and because it's an aggressive schedule, sometimes it may seem like we're not perhaps as organized and doing things in the correct sequence that you would like, but we are trying to be responsive to what it says in the PCAST Report, which it used the word boldly, that ONC needs to go boldly into this area and so that is what we are trying to do.

Now, on our agenda today the highlight is going to be to review the public comments that have been received so far. I believe Doug Fridsma is going to take us through that. So there are a couple of things I want to do first. First, I want to check, Bill Stead, I don't know if you're on –

William Stead – Vanderbilt – Chief Strategy and Information Officer
Yes. I made it through the system.

Paul Egerman – Software Entrepreneur
Great. So did you have anything to add to what I just said?

William Stead – Vanderbilt – Chief Strategy and Information Officer
No. It was on target.

Paul Egerman – Software Entrepreneur
Okay. Now, the other sort of bit of administrative work before we get to Doug I wanted to mention is that a few minutes ago, for the Workgroup members, Judy Sparrow sent out an e-mail that has in it an attachment that is the February 15th and February 16th hearing agenda. One of the things that we're going to ask from you, the Workgroup members, is we really need your help in making sure that we get this agenda done right. Because it's coming so fast there is this great sense of urgency, so if you were able to get that e-mail and open that Word document what you would see is the way we're organizing the hearing, at least tentatively is there are five panels on the first day. Panel Number One is an overview of the PCAST Report. Panel Number Two is patients, consumers and privacy advocates, so basically patients and consumers. Panel Number Three is healthcare providers, which is individual providers and also hospitals. Provider Number Four is health information exchange and various healthcare information exchange stakeholders. Number Five is a population health, in other words, research areas. The last panel is technical panel; it says, "Technical Panel," but it's really vendors or people who are trying to meet the various requirements. In fact, the first five panels are people who for the most part are beneficiaries of what we're trying to accomplish and the last one is the people who are people who are trying to accomplish these results.

When you look at the agenda you'll see there are some places where we filled in names. There are a lot of places where it says, "TBD," and where it says, "TBD," to be decided, are places where we would very much like to have input from you. If you know somebody who you think would be very good to play the role of whatever is described in that slot. When I ask for input though what I'd like to ask you to do is like to send an e-mail to me and to Bill Stead and Judy with your suggestion. Because we're on a public call I don't want to like accidentally cause any problem for any individual by calling out their name and somebody says I don't think they're so good at whatever you think that is. I don't want to do it that way, but if you could give us any suggestions about any of these names we need them. Where we would particularly like to get suggestions is if you have any ideas of organizations or situations where this kind of a universal exchange language or tag data elements for exchange, places where that has occurred on some broad basis and there are some success stories to look at. That would also be something that would be extremely beneficial to have.

Leslie Harris – Center for Democracy & Technology – President & CEO
Can I ask a question? This is Leslie Harris.

Paul Egerman – Software Entrepreneur
Sure. I'm sorry. I'll just remind everybody when you speak, please say your name first.

Leslie Harris – Center for Democracy & Technology – President & CEO
This is Leslie Harris –

Paul Egerman – Software Entrepreneur
Thank you, Leslie.

Leslie Harris – Center for Democracy & Technology – President & CEO
There is actually a history of an attempt to use tagging for privacy. It was called P3P and there was a whole history. I'm not quite sure who can talk about the history of P3P, but this isn't the first time it's been tried.

Paul Egerman – Software Entrepreneur
Is that –

Leslie Harris – Center for Democracy & Technology – President & CEO
It was a more general effort for consumer privacy. I don't know whether it's useful to have somebody there. I mean I can go off and figure out who the right person is from probably an academic or from the World Wide Web Consortium, but there have been efforts to use tagging specifically on privacy and I don't know whether that's useful.

Carl Gunter – University of Illinois – Professor
Yes. It's Carl Gunter. Yes, P3P is a good analogy here.

Leslie Harris – Center for Democracy & Technology – President & CEO
Yes. I actually –

Carl Gunter – University of Illinois – Professor
It was for Web page privacy and we could –

Leslie Harris – Center for Democracy & Technology – President & CEO
Oh, it was for Web page privacy. Right.

Carl Gunter – University of Illinois – Professor
Yes. We can surely find –

Leslie Harris – Center for Democracy & Technology – President & CEO
It was all we had at the time.

Carl Gunter – University of Illinois – Professor
Yes.

Leslie Harris – Center for Democracy & Technology – President & CEO
I mean I don't know – this isn't the first time we've done this.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
This is Wes. I think any real world experience in this would be –

Leslie Harris – Center for Democracy & Technology – President & CEO
Right.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Extremely helpful.

Leslie Harris – Center for Democracy & Technology – President & CEO
Please, let me just go off and figure out –

Paul Egerman – Software Entrepreneur
Yes, so if you could research that, Leslie –

Leslie Harris – Center for Democracy & Technology – President & CEO
It's Christine and me, but we'll kind of figure it out at our table.

Paul Egerman – Software Entrepreneur
Yes. If you could research that. Unfortunately, as I said, we're on a time frame though –

Leslie Harris – Center for Democracy & Technology – President & CEO
No. No. I can –

Paul Egerman – Software Entrepreneur
If there's any chance you –

Leslie Harris – Center for Democracy & Technology – President & CEO
... find out now.

Paul Egerman – Software Entrepreneur
Today that would be great.

Leslie Harris – Center for Democracy & Technology – President & CEO
I'll find out now.

Paul Egerman – Software Entrepreneur
This is Paul. I agree 100% with what Wes said. Any real world experience would be helpful. I mean does anybody else have any other ideas in addition to P3P?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
This is Dixie Baker. The Private Access, who was one of our participants in – the Tiger Team, remember, had the hearing on consumer choice and they at least have real world experience in the research world and are trying to move what they're doing into broader healthcare, but it is used in the research world.

Carl Gunter – University of Illinois – Professor
This is Carl Gunter again. Two of the things that I know of on the data tags beyond P3P is military systems use data tags, the classifications and compartments. Then there is the use of data tags for digital rights management, so XRML and the MPEG standards. So those are other real world experiences.

Leslie Harris – Center for Democracy & Technology – President & CEO
Yes. This is Leslie. There is, I think, some discussion going on at ITS and standards ... right now.

M
You know, I would like to see what's happening there, but I'm really interested in people who've tried the concepts and have some feedback on where they're working and where they need more work.

Leslie Harris – Center for Democracy & Technology – President & CEO
Okay.

M
Yes.

Leslie Harris – Center for Democracy & Technology – President & CEO
Well, I'm sending an e-mail right now on P3P.

Paul Egerman – Software Entrepreneur
This is Paul. The ones I heard were P3P. I heard Dixie say Private Access, if she could send an e-mail on that?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
I will.

Paul Egerman – Software Entrepreneur
Somebody said something about the military?

Carl Gunter – University of Illinois – Professor
Yes. Carl Gunter. Military systems use tagging.

Paul Egerman – Software Entrepreneur
Okay. Do people think that would also be interesting to discuss?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Well, it's not privacy tagging. That's sensitivity level tagging and it's multi-level and compartmented. In my opinion it's a different animal.

Paul Egerman – Software Entrepreneur
Although I don't think it necessarily has to be privacy tagging.

W
No, not at all.

Paul Egerman – Software Entrepreneur
This is Paul. Picking up on what we last said is I think just a few real world examples would be helpful, because otherwise –

Carl Gunter – University of Illinois – Professor
Yes. It's not for privacy, but it does show some things about scalability and some of the issues with tagging, pro and con.

The other one is digital rights management, so the tags for the use, say, of movies that are downloaded and that sort of thing. The PCAST Panel actually explicitly mentioned that as an example of the kind of tagging. You can use that for privacy tagging. There have been some various research papers looking at whether it could be done for privacy tagging.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
This is Wes. The interesting point here though is that digital rights management, at least in the areas I'm familiar with, which are distribution and maybe media, is a pretty simple model. You have rights to it or you don't. The proposal is for many very nuanced models of access and I think one of the important questions at the end is the degree to which the simple model can be or has been somewhere extended to brokering a complex set of rights using the same techniques.

M
The DRM things may be and from instances of actual use simple, but if you look at systems like XrML they're actually quite expressive.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Well, again, the question is not is there a mark-up language written somewhere to express it. The question is how does it work to use it.

Paul Egerman – Software Entrepreneur
This is Paul. I'm trying to understand, Wes. Are you saying that the military example is not a good example?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
No. The military example may be better in the sense that at least it's a more complex model of controlling access than simply you have and you don't. I mean we've had a case in healthcare where we have a very extensive model that has been tested in non-production situations quite extensively for access, but it's different, but nonetheless, it's there. As we took testimony on it last year, it became clear to me that the issues were not is there a technology that can do this. The issues were is there a technology that can be rolled out across the heterogeneous healthcare system that can do this.

Paul Egerman – Software Entrepreneur
Okay. So –

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Paul, this is Dixie. I think it would be worthwhile. There are several of us on this team who participated in the hearing that Wes is referring to. It would be useful, I think, to share the results of that hearing to other PCAST Workgroup members, who may not have heard it.

Paul Egerman – Software Entrepreneur
This is Paul. I think that's great. So let me suggest, because again, I'm sort of squeezing this into the agenda, but if everybody could e-mail to me, Bill Stead and Judy your suggestions and the more specific you can be, in other words, if you can say here's the person at P3P who should testify or here's the person at the military system who knows something, who is experienced, who can testify. That is very helpful.

With regard to the hearing, Dixie and Wes, if you could point out the ones that you think might be particularly important possibly to come back and talk to this group or alternatively, we can also circulate the testimony that some of those people already gave that would be useful information also. So, if you can think -

William Stead – Vanderbilt – Chief Strategy and Information Officer
This is Bill Stead. Just to put a fine point on it, the thing we're interested in is examples of use at scale.

Paul Egerman – Software Entrepreneur
Yes.

William Stead – Vanderbilt – Chief Strategy and Information Officer
That's really what will help us the most.

Paul Egerman – Software Entrepreneur
That's correct.

Mark Rothstein – University of Louisville – Chair of Law and Medicine
This is Mark Rothstein. Can you hear me?

Paul Egerman – Software Entrepreneur
Yes.

Mark Rothstein – University of Louisville – Chair of Law and Medicine
I have a question and that is where exactly on the agenda would the commentary come from on the issue of either assuming that this is technologically achievable, whether it's a good idea and whether it reflects good policy and whether there are unintended consequences and whether it's better than other options and that sort of thing.

Paul Egerman – Software Entrepreneur
Those are great issues, Mark, but part of our direction was not to judge the PCAST Report, so I think the issue is that we're not going to be necessarily going through things and saying this is like whether or not what it says in the PCAST Report is a good idea or a bad idea, although as we go through it if there are things that are problematic, if people say as it's written this doesn't work for HIPAA or for privacy policies that's important to know. What would be most important to know would be if we can come up with alternatives that accomplish the same thing that PCAST is trying to do, but it works better on the privacy side.

Leslie Harris – Center for Democracy & Technology – President & CEO
This is Leslie. So under providers and hospitals I'm assuming, for example, they'll talk about impact on workflow and feasibility –

Paul Egerman – Software Entrepreneur
Yes.

Leslie Harris – Center for Democracy & Technology – President & CEO
So I think people will be developing –

Mark Rothstein – University of Louisville – Chair of Law and Medicine
Well, I'd certainly like them to be invited to comment on the issue of whether they would envision, for example, physician opposition to a system in which patients had such granular control of their health information.

Paul Egerman – Software Entrepreneur
Those are good questions, because here's another way that you can be helpful and that I would like to request your participation in this process is there is a list of five general questions that we're asking. One of them is time frame and the others are like can you come up with alternatives, but what you just said, Mark, in terms of a question to ask the panelists from providers and hospitals. I mean that's a great question that you just asked. So, again, there are questions that you want the panelists to respond to. Let's –

Mark Rothstein – University of Louisville – Chair of Law and Medicine
I could just submit a list. Sure.

Paul Egerman – Software Entrepreneur
That would be good. What I'd like to do is just ask everybody to think about it, but also, it's unfortunate timing, but submit your lists today though.

Gary Marchionini – University of North Carolina – Dean & Professor
This is Gary Marchionini. I'd like to reinforce that one of my concerns is from sort of the patient's point of view whether people are going to be actually assigning these privacy settings at different levels of granularity. We know that people pretty much accept defaults and what will probably happen, I would guess, is that people will either accept full disclosure or not and all of these levels in between, especially at the field or record level are going to be extremely hard for patients in particular to manage and so as these people are addressing the panel I certainly hope that we would ask them to talk about the experience of actual implementation at scale other than people or folks who are getting paid to do that.

W
I really agree with that. People can set their Facebook –

Paul Egerman – Software Entrepreneur
Right. So these are all great comments and so, again, what I'd ask you to do is to put these issues in the form of questions that we want the panelists to answer so that when we do that they'll answer that in the context of their written testimony to us, their written response and also in the verbal comments and that will help form or structure some of the discussion. These are great comments.

So I don't know; does my request on this make sense? Is this doable?

M
Sure. We can get questions to you.

Paul Egerman – Software Entrepreneur
Terrific. So that's great. The other thing I would again remind you of is as you go through the panels if there are individuals who you think would be like really ideal to provide some testimony, especially in places where we have "TBD," where we really don't have anybody, but you think that they have a lot of good perspective and what we're looking for, to make sure everybody understands these panels, is we're looking for a broad range. I mean we'd like to hear people say on any particular topic this is wonderful or this is usually problematic and here's why, but we'd like to hear all of the opinions. It's not like we want to

hear just a single opinion on this, because that's part of the benefit is getting exposed to a lot of different views. So if you have somebody you think would be responsive to anything, please let us know that.

Also, are people comfortable with the way this is structured? Where there's really a full day of presentations, possibly on the second day a little bit more of discussion from people who have real world experiences and then we're trying to get several hours for the Workgroup to discuss; it would be a public meeting, but in person; our reaction to all of the material we've heard so far?

M
Will all of the panelists be attending all of the panels? In other words, are they going to be part of the discussion?

Paul Egerman – Software Entrepreneur
Well, it's up to them whether or not they attend the panels. Usually they present, but this hearing will have a lot of people attending, because in addition to our Workgroup, all of the Policy Committee members and all of the Standards Committee members will be invited and so the panelists usually, after they've finished with their panel, usually they sit in the audience with everybody else, although sometimes occasionally they will be asked a question. So they usually do not continue to participate in the hearing.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
This is Wes. I think we've done an important job here in focusing on finding a way to it's practical to manage privacy rights, but this approach is also about big data, which is a buzz word that I almost missed it came up so fast, meaning data on a scale that wasn't really imaginable only a few years ago in the technology. There are various efforts in industry, typically intra-corporate rather than national, but there are various efforts going on and it might be quite valuable to get some feedback from sort of the early adopters that can show us that this way is not entirely speculation. I don't have a person to suggest right now, but if you think it's a worthy topic I can look through my colleagues to try to find somebody.

Paul Egerman – Software Entrepreneur
This is Paul. I think what you suggested, Wes, sounds good. Again, what we're looking for is some real world experience.

Carl Gunter – University of Illinois – Professor
This is Carl Gunter. I think that's a very good point. One of the things that comes up here is are we at a technology crossroads where some of these things, once thought not to be possible, are now possible? Last week I saw a presentation from Craig Monday as part of the PCAST Report where he listed 12 maturing technologies that underpin their confidence that the things in the PCAST Report can be done. We can't have 12 people testify and Craig Monday, I think, will be there, but I think it's a very important point that a lot of these things are related to we can now do things we didn't necessarily think we could do maybe ten years ago.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
With no disrespect whatsoever to Carl, my business is talking to vendors about what their products can do and how they're evolving and I get enormous amount of value with going to their leading adopter users and talking about what their experience is as an early adopter. The early adopters are always discovering the boundaries and then giving the vendors challenge to work against the boundaries. It's often enlightening to see the difference between the vendor's view of a certain project and the implementer's view.

Carl Gunter – University of Illinois – Professor
It's Carl Gunter. I don't disagree at all, Wes. I think that's a good point.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Yes. So I'm saying, again, no disrespect at all, I think going to the implementers of those technologies that Craig described would be quite illuminating for us.

Carl Gunter – University of Illinois – Professor
Yes, I think so.

Paul Egerman – Software Entrepreneur
So; this is Paul; I'm listening to all of this and I'm thinking these two days we're going to spend together on February 15th and February 16th are going to be fantastic because we have very interesting material. So be sure to send the e-mails with your suggestions for names, any suggestions for real life experiences, additional questions that you want to make sure specific panelists, like providers, answer and we'll work on including all of that.

I hate to do this, but I want to make sure we keep moving on the agenda. The main topic of what we wanted to talk about today was to make sure that we had a presentation on the public comment that has been received so far by ONC. I believe it's Doug Fridsma, who is going to present that to us from ONC. Are you on the call, Doug, and ready to go?

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
I am here and yes, I am ready to go.

Paul Egerman – Software Entrepreneur
Terrific. We just need to get the right presentation on the Web site.

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
There we go.

Paul Egerman – Software Entrepreneur
Terrific.

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
So, let's go to the next slide here for just a minute.

Paul Egerman – Software Entrepreneur
Okay. I don't mean to interrupt you, Doug, but perhaps you should also introduce yourself to the group. Not everyone knows who you are.

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
Sure. I apologize. My name is Doug Fridsma. I'm the Director of the Office of Interoperability and Standards at the Office of the National Coordinator. I've been working with Jodi on a lot of the PCAST Working Group activities. Jodi is in the Office of Policy and Planning. So together, both the policy aspect of the PCAST Report, as well as the technology aspect, we've tried to, within ONC, bring those groups together and make sure that we can address any of the concerns that might come up. Our job is really to try to provide this particular committee, the Working Group here, with the resources and the analysis and the information that you need to provide us the best analysis and input. So this is one of those instances in which what we've done is, as part of the publication of the PCAST Report, we put out requests for public comment and that just closed a couple of days ago and we've been beginning to do some of the analysis and to provide some feedback to the committee.

I think it's really important to understand that I am a neutral body here. This does not reflect any of the positions of the Office of the National Coordinator, but we are here to try to take that public comment, to synthesize it, to provide whatever analysis that this particular committee needs and if there is additional information we can provide, but we aren't going to be able to answer questions like what did they mean by X, because our goal here is to just provide support to the committee and not to provide interpretation.

So we can go to the next slide: Just to give you an outline of kind of what the work process has been to date, on December 8th the Presidential Council of Advisors on Science and Technology released the PCAST Report. On that same day we published a request for comment asking the public nine questions

regarding the impact of PCAST on ONC activities, initial thoughts about those recommendations and how the public wanted ONC to act on those recommendations.

The public comment was due by January 19th and since that time we've been collecting and kind of bringing all of those comments together. We received 107 comments and this particular presentation will be our attempt to sort of summarize and categorize and group those things together.

So if we can go to the next slide: Just to give you a sense for the kinds of comments that we have, I understand that it was only about ten days ago that we actually closed public comment and there's a series of steps that have to happen within the federal government in terms of us then getting access to those things and we've been doing some of this analysis here, but we certainly are, by no ways, complete. We did receive comments from about, when we look at the comments that we received and we break them down in terms of who we received comments from, about 35% of our comments were from associations, EHR and PHR vendors and HIT software companies. About 15% of the comments were from folks that had expertise in infrastructure, health information exchange organizations or SDOs. Twenty percent came from providers, pharmacy organizations, hospitals or health plans and about 30% included patient advocates, individual citizens and state health employees.

So I think we can do additional analysis as needed for you. We can also provide additional linking, but that at least gives you a sense of both, the number of comments that we received and the folks and the kind of distribution of what those comments are like.

If we go to the next slide, slide five: We tried to bucket a lot of the comments together and so we've looked at it from five different common themes. There were comments around timeline issues in terms of the recommendations that we received. Some of them were related to the effect on ONC programs, specifically targeted to certain programs within ONC. There were recommendations about process, about how we should go about to the next step in terms of implementing PCAST and the recommendations. There were comments regarding privacy and security issues. And finally, there were comments regarding standards to support the PCAST recommendation.

Next slide: So what I'd like to do in the subsequent slides is to take each of those themes and to go through each of the questions, first, telling you what the question was to remind people of what the question was in the RFP and then to give you a sense of the kind of responses that we've received. Again, I just want to emphasize that our goal here is if there are kinds of analysis that you want us to do on this data, if there are ways that we can provide this information to you in a productive way that will allow you to make good deliberations and analysis that's really the goal here. I'll go through each of the questions and sort of talk about what the comments were, at least within those buckets, and then what we'll do is I'll try to summarize at the end.

The first question was broken into three parts and so question A and B basically said what standards implementation specifications, certification criteria and processes for EHR technologies and other health information technology would be required to implement the following specifications, specific recommendations for PCAST. One was that ONC establish minimum standards for metadata associated with the tag data elements; and two, that ONC would facilitate the rapid mapping of existing semantic taxonomies into tagged data elements.

If we go to the next slide: We received a number of different comments regarding this and these comments here were predominantly in two buckets. One was the process of implementing those recommendations and the second was around standards. So the kinds of things that we heard were that the recommendations were for us to use an open, consensus driven process; to not re-invent the wheel and to leverage existing metadata standards, registries and existing taxonomies and vocabularies; and try with whatever we do, to keep those requirements to a minimum.

With regard to standards, they said that there was a need really to take a look at existing taxonomies that were out there and that the industry needs widely available, harmonized taxonomies, including things like SNOMED CT to ICD-9/ICD-10.

There were comments regarding clinical content in that the true meaning of data could be lost when tagging at an atomic level and it will be important for us to think about that as we proceed.

There was discussion about choosing the right granularity of data tagging, so there may be a data set level. One suggestion was a data set level might be the happy medium between document level and atomic level and that there was a request to use a model driven approach to the tags, terminologies and value sets informed by an information model.

If we go to the next slide: Question 1C, just to remind people, again, this is what would be required to implement the following specific recommendation and the question in part C was to look at certification of EHR technology, It should focus on interoperability with reference implementations developed by ONC.

The summary of responses to those questions, if you take a look at the next slide, question 1C, really were in sort of three buckets here. So there were timeline issues. There were recommendations to have an incremental process that used pilot demonstrations to try to reduce the future risk on the program or on the approach that PCAST would use.

One of the effects on the ONC programs is that they wanted to make sure that certification was based, as much as possible, on ONC developed reference implementations to make sure that they could realize the opportunities identified by PCAST and that there was an emphasis on creating these real world validations of the PCAST concepts, give them a solid base for certification and that there may be a need to validate data at rest and during the interchange.

Go to question two. Question two in the RFP said, "What processes and approaches would facilitate the rapid development and use of these standards, implementations, specification, certification criteria and the certification process?"

Go to the next slide. These are broken down kind of into sort of three buckets here. One was the effect on the ONC programs and that there should be incentives to the development and adoption through federally sponsored programs. So using CMS, DoD, ONC and other programs to help incentivize the development and adoption of these recommendations.

With regard to the process of implementation, again, the notion of achieving broad industrial participation built on openness and transparency and again, building on processes that work, so using existing projects and processes, such as IHE, MITA, the Direct Project, for example, and building on those as we move forward with the recommendations.

With regard to standards, again, this notion of incentivizing through federally sponsored programs and another theme that came up was providing common tools that enable development collaboration, development of pilots, testing for efforts, such as mapping terminologies and taxonomies together.

We tried to lump some of the other questions together as well, so if we take a look at the next slide, looking at questions 3A and 3B: Those questions were given the currently implemented information technology architectures and enterprises, so what's out there right now, what challenges will the industry face with respect to transitioning the approach discussed within the PCAST Report. That was broken down into sort of two buckets, two sections.

One was given the current implemented provider workflows what are some of the challenges to populating the metadata that may be necessary to implement the approach discussed. And alternatively, what are proposed solutions or best practices from other industries that could be leveraged to expedite these transitions. So one was sort of what are the challenges that we have with current workflows and can we look at other industries and leverage their expertise to help us with some of the recommendations within PCAST.

So again, we received a number of responses from the public on this, the first with regards to the process. They said providers must have general availability of sufficient broadband and computational resources before they could implement the PCAST recommendations. This was sort of a general infrastructure question; that we needed to have sufficient broadband so that the providers would have access to the technology that PCAST was recommending.

M
Do we need the slide to be advanced?

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
Oh, I'm sorry. Next slide. There we go. Thank you.

The second one was around privacy and security issues and that atomic level data tagging may further the effect on patient identity and matching issues, as well as issues of data ownership. That was an issue that we needed to address that, in fact, patient identity and matching become an important aspect that we will have to look at and that it would also be included in these approaches.

With respect to standards, there was the notion that we have to have consensus on the correct level of data granularity. This is something, again, echoed in some of the other responses; that new PCAST standards should harmonize with existing systems and standards to maintain the workflow dynamics and avoid potential patient safety issues that could be introduced with the changes in the workflow and that we needed to build on existing document level tagging approaches instead of atomic level tagging or at least enable interoperability among the two.

Next slide. Question number four said, "What technology developments and policy actions would ... to assure privacy and security of health data in a national infrastructure for health information technology that embodies the PCAST vision and recommendations?" So what work on technology and policy, particularly as it relates to privacy and security, would be needed?

Next slide, Question Four, the Summary of Responses: Suggestions here included the need to implement granular consent and data segmentation that would allow for dynamic privacy metadata so that patients could update their privacy preferences. That was an implementation issue that we needed to address.

Second was design of granular patient privacy control features should be patient centric and not data centric.

With regard to privacy and security issues in particular, there were a few comments based on the DEAS recommendations within the PCAST Report and that suggested that that infrastructure must ensure public trust by performing risk analysis; upgrading outdated privacy policies that do not take into account the health network; having infrastructure that is certified; having reliable patient identification and having built-in technology solutions for patient identification without acceptable false-positive rates. Maybe that should be with. Finally, that data sharing infrastructure must have acceptable accountability and oversight framework and should avoid an over reliance on consent.

Question number five; go to the next slide; this is slide 16; suggests how might a system of Data Element Access Services, the DEAS, as described in the report be established and what role should the federal government assume in the oversight or governance of such a system.

We can go to the next slide. The summary of responses here, outside of privacy and security concerns, commenters had the following input regarding the DEAS. One commenter suggested that financial incentives may be necessary to spur development of these DEASes. Commenters also acknowledged that multiple models exist on which DEASes could be structured and governed. Suggestions included using a service oriented architecture or having the DEAS reside within a health information exchange. However, there was really no predominant opinion among the comments received for this particular RFP.

On the standards commenters suggested that ONC could make software or an implementation specification available for the DEAS framework, so similar to some of the other responses about a reference implementation that ONC could make software or an implementation specification available for that framework.

Some suggested that ONC examine XDS and the experience of intermediaries, such as Surescripts, and patient record locator services when developing these DEAS implementation specifications to leverage some of the existing work that's out there as we come up with those specifications.

Next slide, slide six: That particular question addressed how might ONC best integrate the changes in vision by the PCAST Report into its work in preparation for stage two of meaningful use.

Go to the next slide, slide 19: Here we have some timeline issues. There was broad consensus among the variety of commenter groups that full implementation of atomic data tagging and DEAS deployment would be difficult to realize in the time frame of meaningful use Stage 2 and Stage 3. Many felt that existing systems could not be upgraded in time and the cost of such systems would be unrealistic.

In addition, there were some commenters that stated that delays in the PCAST time frame may occur while new metadata standards are being developed. However, many felt that it would be timely to have DEAS and other PCAST technologies piloted during stage two.

Sort of the corollary to that is the effect on the ONC's programs. Many commenters asked ONC to focus meaningful use Stage 2 on improved interoperability and connectivity to state systems; value based meaningful use criteria rather than technology adoption goals; outcome research, assessment and quality measures; looking at decision support and examining biosurveillance and biometrics.

Question number seven; next slide; were what are the implications of the PCAST Report on HIT programs and activities, specifically health information exchange and the federal agency activities and how could ONC address those implications?

Next slide, slide 21, The Process of Implementing the PCAST Recommendations: Many commenters wanted to see the government in a variety of different roles. One role would be hosting, as part of the S&I framework, an HIE interface initiative for implementation specifications of the EHR-to-HIE interface, consistent with what's currently in the nationwide health information network exchange.

They also suggested that the government could engage the various state HIEs to which edge EHRs are to be connected, HIE vendors, EHR vendors, other stakeholders, so that there is consistency across the state, regional and community HIEs; including this implementation specification for Stage 2 or Stage 3 and including it in the EHR certification; and establishing a voluntary HIE testing program based on the implementation specifications within PCAST.

Question number eight, next slide: Are there lessons learned regarding metadata tagging in other industries that ONC should be aware of?

Those response, if we go to the next slide, include some timeline issues. Once again, there was a lot of folks that pointed out that no precedence existed in other industries that portrayed the massive scale of metadata tagging, fragmentation and the voracious capacity requirements within the complexity of healthcare information; that implementation using complex metadata may be difficult and so that was something that we needed to address in the process of implementing. And with regard to standards, avoid reinventing standards and learn from successes and the problems experienced within epSOS, which is an EU initiative, HL7 V3 RIM, ASCX12, GIS and some other standards organizations.

Question number nine: Are there lessons learned from initiatives to establish information sharing language, universal languages, in other sectors? So again, another question looking outside of healthcare and seeing if we can draw in any expertise.

The responses to that include; go to the next slide; with regards to standards we should look at banking and the Internet. We might want to look at Data Fusion Senders, such as those that the Department of Homeland Security and the Department of Justice have been working on. We can look at examples of previous standards work to review, including and there is a whole list of things; DICOM, ICAM, LC's MARC, MODS, MADS; there is a whole list of things; Dublin's Core. All of these things are things that we can provide in greater detail to the committee, but there was a lot of existing standards work that the public recommended we examine as we look towards this universal language.

Other things were looking at examples of countries that have looked at health data exchange and so comments included England, which suggested abandoned data level architectures for a CDA model; Finland, which uses a CDA model of exchange; and Europe's sort of Nationwide Health Information Network equivalent, called epSOS, which is using a CDA model of exchange.

So if we can go to the next slide here: Now what I'd like to do is we've sort of stepped through each of the questions and kind of the kinds of comments that we got back. Now what we've tried to do is along those different buckets, trying to put all of those pieces together across all of the different questions that we asked.

With regard to timeline, many commenters were glad to see the PCAST recommendations push towards an increased focus on information exchange before the release of Stage 2 Meaningful Use criteria and certification criteria; however, the majority of the commenters were concerned about the timeline effects of implementing the full PCAST recommendations in the midst of rolling out Meaningful Use Stage 2 and Stage 3 along with other changing standards, such as the change from ICD-9 to ICD-10.

There were concerns that there would be negative effects on patient safety. Many reviewers also specifically recommended that PCAST recommendations be a long-term strategy rather than an immediate deviation from the current groundwork that has already been laid.

If we go to the next slide, slide 27: With respect to the effect on the ONC programs, most commenters urged ONC to leverage successes of current ONC and private HIT programs without reinventing the wheel in the midst of the HITECH incentive period.

Many stated that full implementation of PCAST recommendations would require redesign of much of the ongoing federal HIT grants and contracts, which would incur a substantial cost and may discourage participation of current players.

Many commenters did suggest that ONC begin smaller pilots to develop and test PCAST technology solutions. If successful, those solutions could later be more widely implemented.

If we got to slide 28: With regard to process, many commenters had a common theme of not reinventing the wheel and learning from and leveraging existing standards. There was support for the continuation of health information exchange. It was reflected through the majority of comments with further support to have the health information exchanges and information exchange be the focus of further meaningful use stages.

And third, although many commenters agreed that a DEAS structure would be necessary to implement PCAST recommendations of atomic level data sharing, most cautioned that creation of a DEAS structure should begin with much pilot testing and pay close attention to patient linking and public trust issues.

Slide 29 summarizes the privacy and security comments. With regard to privacy and security, many commenters were very supportive of the concept of giving patients granular consent as envisioned within the PCAST Report; however, there were also worries that tagging patient privacy preferences to the data would lead to a static, rather than a dynamic data control environment that prevented patients from updating their privacy preferences once the data was released.

Commenters from the research community were supportive of PCAST's concept of creating a subset of de-identified data for the purpose of research; however, others were not supportive of this PCAST recommendation because they were skeptical that data could be truly de-identified.

Slide 30 summarizes the recommendations with regard to standards. A few commenters wanted ONC to avoid competition between existing standards and instead move to a completely new approach, as outlined in PCAST, because they felt, one, that current standards are strict and do not allow for innovative (inaudible).

They also felt that the CDA is not a suitable framework for the exchange of metadata tagged elements as it is document centric and exists primarily as a wrapper for many different kinds of documents. However, most commenters stated that the PCAST goals of interoperability and data liquidity can be met with existing and emerging standards, particularly ... by ANSI accredited ... SNOMED and LOINC.

If we go to the last slide, I just want to remind people to keep their phones on mute. With regards to next steps, ONC is currently working on further analysis of the comments received. What I've presented here is really our first blush through the information and our attempt to provide some sort of buckets, some way of kind of organizing this information. We'd like to produce a summary report of those comments that can be available to this Working Group as you do your deliberations and you provide additional comments.

I think with that I want to again emphasize that our goal here is to provide you an unvarnished picture of what the public comments were and to provide the kind of analysis that will be helpful to this Working Group as you consider the PCAST Report and the ONC programs and the variety of questions that were asked with regard to the public comment. So I think the thing that would be very helpful is given kind of this overview of what the comments are that we received, what other kinds of analysis or what other kinds of reports or if you just want to have all of the raw data we can certainly provide those sorts of things to you as well, but how would you like us to proceed in a way that would be helpful to this Working Group to get a synthesis and analysis of the public comment for your use?

With that I'm going to sort of end it and open it up for discussion.

Paul Egerman – Software Entrepreneur
Great. This is Paul. Thank you very much, Doug. Excellent, excellent presentation and a lot of work to put this together in a short period of time, so thank you. This is very impressive. What questions and comments do people have?

Leslie Harris – Center for Democracy & Technology – President & CEO
This is Leslie Harris. In terms of a final sort of summary, I think obviously who commented and some sense of who is saying what is really helpful, even if commenters are grouped with a point of view. It's a little hard to know the depth and breadth of a position otherwise. I don't know how hard that is, but –

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
That is something that we actually intend to provide.

Leslie Harris – Center for Democracy & Technology – President & CEO
Okay.

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
We just didn't have time to –

Leslie Harris – Center for Democracy & Technology – President & CEO
No. I understand.

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
Attribution.

Leslie Harris – Center for Democracy & Technology – President & CEO
I understand we're not at the end of the process here.

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
But that's an excellent suggestion and we certainly will try to provide that to the committee.

Leslie Harris – Center for Democracy & Technology – President & CEO
Okay.

Tim Elwell – Misys Open Source Solutions – Vice President
Doug, this is Tim Elwell. I was curious if in taking a look at page 25 where it calls out specific examples of other countries and success or failures that they've seen, if there is anything that's been published to your knowledge that would have done the assessment of the data level architecture that, for instance, England abandoned or why some of the other countries have chosen the CDA model instead.

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
I'm sure that there have been reports about that. One of the ... is that the literature tends to report on successes and not on changes of direction, if you will. So there is certainly a bias in the literature out there as people have published that sort of information.

I think from my perspective this suggests some additional work; that we probably need to reach out to some of these organizations and have a conversation about helping us understand how their strategy evolves over time. If that becomes a recommendation that we have from this working group then ONC is prepared to help support that kind of data collection.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
This is Wes. I'd like to suggest that the literature is most replete with planned approaches and there are a few cases where successes are provided, in part because there are only a few successes and that an evaluation of alternatives, such as the three, England, Finland and Europe, epSOS here, be careful to stage, to do some tumor staging would be the wrong metaphor here, but would do some staging in terms of where the particular geography or whatever that whatever the unit is, how far they have proceeded along with their currently adopted approach. For example, my understanding is that Finland is quite operational; that epSOS is still in the planning stages. I just don't know where England is with regards to this change, particularly since there have been some other changes in England.

Paul Egerman – Software Entrepreneur
This is Paul. I think your comments there, Wes, are excellent. Also, just a couple of other observations: Apparently, one commenter said that England abandoned data level architecture. We just need to find out more about that, whether or not that's what really happened or what specifically occurred there.

William Stead – Vanderbilt – Chief Strategy and Information Officer
This is Bill Stead. I was beginning to think that one of the things we might do with this is try to tag the comments that might reflect not the correct interpretation of the report or whatever the right way to say that is. So if there are comments, which, as we work through our job of explaining the report, we can identify that they reflect a common misperception, then that will let us help develop communication material that really clarifies it.

I think I'm relatively comfortable that England never considered anything like the PCAST Report. They did, they were doing more granular level exchange than they are currently trying to do, but what they were trying to do was not a data level architecture, at least in my interpretation in the sense that PCAST is. So I think that we could actually note which of these are questions of timing, which are issues of scale, which are issues of feasibility, which are issues of understanding; it might be one way to try, one ... to try to put to organizing the comments and helping us use them.

Tim Elwell – Misys Open Source Solutions – Vice President
Paul, this is Tim Elwell again. I had another question and comment. Relative to analysis that the ONC perhaps could help us with, the timing issue continues to be of major concern it appears throughout many of the comments. When I take a look at the stated mission that we have in making recommendations to the ONC, it becomes apparent to me that there are specific things that are being marched toward, especially relative to the Meaningful Use Stage 2. The question here is is there any analysis that can be performed against the current stated trajectory of outcomes that we're expecting to be able to meet based on our best thinking now and where we want to be by the third stage or third phase against what would be required to be able to deploy this type of option. I just would like to, in some way, look at that trajectory against that meaningful use plan to determine what the impact of that may be.

I don't know how to do that. If there is any input that you could give, Doug, on how we could approach that I think that would help, at least in qualifying our recommendations.

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
Let me just get a clarifying question here. Some of the timing issues could be, as you sort of suggest, if we've got plans within ONC with regard to Meaningful Use Stage 2 and Stage 3 and some of the other activities we could map that against some of the impact that the PCAST recommendations would have with regard to ONC plans, but then there's sort of the other issue, which is given what a particular meaningful use criteria or a standards or certification criteria would require that has to get mapped back into the technology companies, the vendors and the hospitals and organizations that would be required to implement those things as well –

Tim Elwell – Misys Open Source Solutions – Vice President
Yes.

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
There's sort of this backward chain.

Tim Elwell – Misys Open Source Solutions – Vice President
Exactly. Yes.

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
It sounds to me like initially I thought you were just wanting us to take a look at ONC, but you want us to take a look at kind of both of those?

Tim Elwell – Misys Open Source Solutions – Vice President
Yes. I think that there's a domino effect here and there has been a path that many of the vendors have endeavored to work toward in anticipation of what will happen and what's been mandated. The question here now is would the new implementation that's being recommended here, speaking specifically, Doug, to your comment about the impact on vendors and being able to response in an appropriate way, will the vendors be able to meet the requirements and also have product ready to be able to support the Stage 2 and Stage 3 Meaningful use. Does that make sense?

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
No. That does make sense. I think we certainly can provide a framework, not with specific dates and times, but just general plans for what Meaningful Use Stage 2 and Stage 3, much of it is in the legislative mandate that we have in terms of rolling this out and the incentive programs and the like.

Tim Elwell – Misys Open Source Solutions – Vice President
Right. Right.

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
We can map that into some of the existing programs that we have. I think the question about the vendors is probably one that I hope some of the hearings and some of the public comment that we might get from vendors can speak to directly. I think we certainly can help facilitate that, but that's not a question I think

that we should answer. I think that's really the vendor community can help us understand whether or not there is product readiness and to what degree they'd be able to support recommendations that would come out with the PCAST.

Tim Elwell – Misys Open Source Solutions – Vice President
I think though, in all due respect, Doug, that the PCAST Report has kind of stuck their toe in the water already when they've made some estimations as to what the potential costs are associated with deploying these changes. So I do agree with you that it has to be flavored with direct input from the vendors and I would certainly encourage that through public comment and any other standard parameter or metric that you use. But I do think that that's a critical component in trying to help us assess, put into kind of categories what the impact from a time perspective might be.

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
Sure.

Paul Egerman – Software Entrepreneur
This is Paul. Let me make a couple of comments. One of the things that we have been talking about is to try to help everybody address some of these issues is to create some perhaps presentation or additional meeting where we give you, everybody, a little bit more information about what's going on in Meaningful Use 2 and Meaningful Use Stage 3, because we realize there are some people on this call; there are some people on this call who are very actively involved with those things, where some people on this Workgroup, all of that is like new stuff to you. So we'll try to see if we can make sure we bring everybody up to a common level. That's one thing I wanted to say.

The other observation I want to make is as you look at this issue that Tim is raising and it certainly seems to be a consistent theme through the public comment, the issue about timing in terms of what can be absorbed and when can it be absorbed, in some sense that's a challenge that exists in general for ONC for this entire program. We've got to remember that we've got a program here that is voluntary. In other words, this is not a mandatory program; it's a voluntary program. There are incentives and if people want to participate, if they think the financial incentives are significant enough, then they will participate. So the interesting challenge ONC has is to somehow, I call it, like raise the bar incrementally through Stage 1, Stage 2 and Stage 3 the right amount, because if you raise it too high people will say, "The incentives aren't enough. I don't want to participate." If you don't raise it high enough then people will say, "You're just giving away money. It's got to be a bit of a challenge."

So this issue is not unique to this topic. I think it's an interesting issue that exists throughout and ultimately this partly should be reflected in whatever our final report is. As we go through and listen to everybody we try to say here are some alternatives that ONC has to, on the one hand, be aggressive in implementing the PCAST report, but also on the other hand, the incremental and evolutionary and be responsive to what we observe the industry can absorb.

Farzad Mostashari – ONC – Deputy National Coordinator for Programs & Policy
Hello. This is Farzad. You know, one of the really interesting analogies or frameworks for thinking about this problem is the ultra large scale system perspective of a system of systems that have characteristics that we're grappling with here around decentralization, around conflicting, noble and diverse requirements, around the need for continuous evolution and deployment, around heterogeneous, inconsistent and changing elements. The task, therefore, becomes not command and control, but rather orchestration.

W
Yes.

Paul Egerman – Software Entrepreneur
Right.

Farzad Mostashari – ONC – Deputy National Coordinator for Programs & Policy
I wonder if there are some folks in this group; I don't know, Carl or others, who can help us think about how we do this, not thinking about it with an enterprise mind frame, but with an ultra large scale system of systems perspective of how one might orchestrate in this way or perhaps we want to have some speakers be part of the briefing that can bring this perspective.

Paul Egerman – Software Entrepreneur
Excellent comment. That was an excellent comment, Farzad. Do people have any responses to what Farzad said or any other questions for Doug?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
This is Dixie. I would agree with both, Farzad and Tim. It's not a linear how high is the bar; it's really exactly what they're saying. It's a matter of getting, orchestrating multiple trajectories to be explicit. That's the challenge. I agree with Farzad; if we could get somebody to address that perspective in our hearing that would be useful.

William Stead – Vanderbilt – Chief Strategy and Information Officer
This is Bill Stead. I think the part that could really make it useful, when some people think about evolution they think about making the changes to do something like PCAST within the context of our existing systems. What somebody from the ultra-large scale systems community could help us think about is we've got our current systems. We're going to continue to deploy them. They're getting us on a trajectory. We actually don't want to disrupt that, but it's quite possible that we could set a parallel infrastructure in place and begin to make it easier for our current systems to do what they do while building out that parallel infrastructure and in essence, you're able to evolve by creating a capability that sits beside the current infrastructure instead of by actually having to change the current infrastructure. If somebody could help us see that idea of an evolutionary path I think it might help.

Carl Gunter – University of Illinois – Professor
This is Carl Gunter. On the things about the scale, if you look at these technologies that give evidence of the scalability of some of our existing capabilities, one of the features that you see is often there are things that have been demonstrated in large scale, but within a single enterprise and so one of the challenges will be to figure out how some of these things can be done between multiple enterprises and probably necessitating some of what Bill was saying, which is ways in which the inter-domain function can rest aside the intra-domain functions. So one sees a very strong analogy; I can't help but look at this and think of it as having a lot of analogies with the Internet design where one has to deal with this differentiation between the intra-system and the inter-system.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Yes. This is Wes. I'm thinking of some classic examples of large-scale systems, like SABER and the credit card clearance system. It's interesting to notice that the SABER either directly ... directly follows Carl's point, except that the N isn't one, but it's a small number. It's less than 100.

I believe, in fact, the corporate entity was created and subscribed to by the others with governance that's sort of the equivalent, in our case, of some one entity building the Nationwide Health Information Network and having contracts with everybody that uses it.

The credit card clearance is a little different in that regard, but it's all transactional; that is when you sign up to do it you know exactly what the outcome of this transaction is, what data is involved. We're looking here at a network that's designed for unanticipated discovery over time. So I think there is a lot to be learned by addressing the question that Carl has put out.

Carl Gunter – University of Illinois – Professor
And going to Wes' point there, one thing I thought particularly looking at this is that you don't want this to be like the way the Internet was designed; that the analogies are probably closer to the two he gave, like SABER and the credit card clearance system where there is some concept of an insider entity that's under a governance agreement and then access into that system from a wide range of parties, because

we don't want to end up with another system that has the features of the Internet with respect to security and privacy.

Paul Egerman – Software Entrepreneur
Sure. This is Paul. These are all excellent comments. I just want to remind you that the topic that we're talking about right now is Doug's summary of the public comment. One of the challenges we have is there are so many interesting things that we can discuss coming out of almost anything, but particularly the public comment. I want to make sure I return ourselves to Doug's presentation and find out if there are other questions people have about the presentation, if there is material we need, because we want to make sure that we have an understanding of these 100 or so responses that were received.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I think we've stated already that there are areas in the comments that cite experience in other industries or other countries and we're interested in some drill down –

Paul Egerman – Software Entrepreneur
Okay.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
To validate and place in context those experiences. I think we should look specifically at the comments other than the three country comparisons there and see if there are other areas, a few other areas that would benefit by some focused drill down just to get the facts.

Paul Egerman – Software Entrepreneur
Okay.

Gary Marchionini – University of North Carolina – Dean & Professor
This is Gary. I just want to also make sure that we don't lose that earlier comment about trying to have the analysis by stakeholder group so that we can try and understand what some of the motivations for some of those comments might be.

Paul Egerman – Software Entrepreneur
I appreciate that comment to that you just made, Gary, and also I think Leslie made that comment originally, so that's correct. Let me ask a simple question. Are all of these comments on the Internet somewhere or is there a way for us, if we wanted to read the raw data, to actually get it?

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
I don't think that they've been posted on the Internet, but we can provide you all of the raw data if you'd like. That's not a problem at all.

Paul Egerman – Software Entrepreneur
Okay.

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
Let me just sort of summarize, Paul, the issues or the sort of to-do list, if you will, about some of the things that ONC can do to help provide support to the Working Group.

Paul Egerman – Software Entrepreneur
That would be helpful.

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
I think number one was that we need to have attribution. We'd like to know who said what so that we can interpret those comments in light of whether it was an individual, an organization and what their particular perspective might be.

Number two: With regard to evaluation of different approaches, there was, I think some additional research that's needed on the other experiences, particularly across the different industries and the different governments that ...; that we also need to make sure that we understand how far they proceeded with their current approaches. So Wes had made the comment about there's a lot of proposed plans, but what we really need to do is take a look at what gets operationalized.

Number three: I'm not quite sure how to do this, but we will take it as a challenge to tag comments that have some sort of misconception; I think this was a comment that Bill had; just so that we can try to help provide some communication around that.

Number four was a timing issue and that the committee wanted to understand a bit more about what the plans were for Meaningful Use Stage 2 and Stage 3 with regard to the various programs and to think about that with regard to the domino effect that might have on vendors to be able to bring things forward.

Then I think, finally, there was a comment that Farzad raised and that Dixie has mentioned about kind of the ultra large scale system. I have a note here that we may need to get some expertise and some information to the panel about the ultra large scale systems and to really think, as Bill had articulated, this notion of incrementalism and maybe having things in parallel, but making sure that we have a way to have those systems work together.

Those were the five things that I have listed. I don't know if I've missed any, if there are any that people want to add.

Hunt Blair – OVHA – Deputy Director
This is Hunt Blair. I wanted to make two comments. First of all, as to Farzad's contribution and the follow-on from Dixie and Bill, I think that ... is an excellent one for us to look at, because I think there is a lot of paths forward from here that we can explore there.

Then secondly, just thank you very much for the summary you did. I mean to take 100-plus comments and reduce them, not reduce them, but distill them to the presentation you did was extremely helpful, so thank you for what I know was a huge amount of work.

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
Well, thank you.

Paul Egerman – Software Entrepreneur
I agree. Doug, that was excellent. Any other comments before we move on?

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability
Well, I can say one comment is that in ONC this is not a single individual doing this. We've had a team of folks that have been working on this, both between my office and with Jodi's office. We will convey the thanks to them as well for the work that they've done.

Paul Egerman – Software Entrepreneur
Yes. It is terrific and it does appear to be that there must be a lot of people working, because there's a lot of good work coming out of it. It's great. So thank you very much, Doug.

The next topic that we have may seem a little disconnected from the last topic, but in our very first call there was a request; I think it was Leslie that made it; to look at some actual, specific examples to sort of compare or try to compare what PCAST is suggesting with what is currently being done with Meaningful Use Stage 1, with this thing that's called CDA. So we have a hopefully short slide presentation to try to respond to that, to try to see if we can make some of these things tangible so you actually see some specific examples.

If we could load back in the original slide presentation? Is that possible to do? Do I do that? Judy, if we could ask them to put back in the –

Judy Sparrow – Office of the National Coordinator – Executive Director
Yes. Let me check with Altarum.

Paul Egerman – Software Entrepreneur
Okay. We'll have quite a public comment here. There we are. Perfect. So here is what we tried to do and to use a word that Bill Press used, some of this is like a cartoon as to how the system works, so as I go through this there are many people on the phone who know this far better than me, interrupt me when I make a mistake or when you want to make a point.

Basically we have three use cases. Use case number one is trying to be used to illustrate sort of like the current technology concepts for something called the CCD, the Continuity of Care Document that will be used in Stage 1 of Meaningful Use. Just so everybody knows, Stage 1 of Meaningful Use started on, I guess, January 3rd in terms of registration, so it looks like we're 24 days into Stage 1 of Meaningful Use.

Now, in this use case there is a patient that presents to the emergency department complaining of severe chest pains that were suffered when the patient was doing a home improvement project. In this use case basically the ED clinician is able to, it says, "Retrieve," is actually able to look at a CCD patient summary from another organization, which contains important information that is needed to treat the patient. It includes an active medications list, along with a problem list. This is an example of what that looks like.

What you see here is this is what, again, stage one of meaningful use would produce for this sort of use case. You'd see on the left a list of problems. You see five problems listed. The first one, I'm not a physician, says, "Tachycardia." That sounds like some cardiac something. So that perhaps is relevant to the fact the patient has severe chest pains.

In the second column you see a list of medications.

In the third column you see vital signs.

In the fourth column you see immunizations.

Towards the bottom you see allergies and I guess there's an allergy in this case to penicillin. You see some laboratory work.

So what you're looking at here is possibly what might be viewed in the emergency department. This is not; for people who perhaps are not familiar with medical records; a patient's complete medical record. This is sort of like a summary. It's sort of like Cliff Notes of the patient's medical record.

Also what you're looking at here is a patient summary of a human being who is actually very healthy. If this were somebody who was not as healthy you would see a lot more problems listed, certainly a lot more medications listed. These laboratory results; it looks like SAT upper 99th percentile. These are good numbers for basically a healthy person, but the concept is this information is provided to assist and giving sort of a snapshot on the patient and hopefully it's responsive to what's required in the use case.

What we wanted to show is what is underneath that. What you see here that is written in very tiny font on your screen is indication that the current continuity of care document is actually written in XML. So if people want to know what XML looks like, what tagged data elements look like, if you look at like the third to the last line from the bottom you see where it says, "Postal code," in brackets and it says, "17701," and then it says in brackets, "/postalcode," well, in effect that's what this is all about. It's a tagged data element, postal code. It's like the metadata. It tells you that the next thing you see is the postal code and the thing that comes after it with the slash sort of says postal code is done.

When people talk about XML versus other languages what they're really talking about is syntax as to whether or not you have the postal code with pointed brackets or something with square brackets, whether or not you have the thing at the end with the slash. There are a number of different syntaxes, but

this is sort of to show you that fundamentally this continuity of care document doesn't get delivered as I showed it to you, as an actual document. It actually gets delivered with all of that XML code and it is delivered though. It's not assembled from multiple sources. It really generally is delivered from one source; it's, in this case, the emergency department hospital computer system, but is also delivered in a format that is computable so that at least in theory once it's in that system if the physician were to order, for example, a medication it would check automatically against the allergies and give you an alert if there's a problem with penicillin. It would check against, say, the problems and it would say this medication you just ordered has some indication not to be performed if the patient has glaucoma. So it would give you some alert, so it is actionable.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Paul?

Paul Egerman – Software Entrepreneur
So let me pause there.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Paul, this is Wes. Can you go back to the XML slide for a minute? I'd like to make a comment.

Paul Egerman – Software Entrepreneur
Sure.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I think it's important to recognize that the postal code and state and so forth are as Paul described it. It's also important to recognize that we're only seeing a part of it, but there's a notion of some of these things being within others. So at the very top there's a tag that says, "Clinical document." Everything in there is related to clinical document. There is a title that says what kind of a document it is. There is a time so we know what time this particular reference, this particular report describes. It's not the time It's prepared; it's the time of the patient data.

Then postal code is inside a set of tags called address. They're inside a tag called patient role. You can't see the closing one, but that says that this is the address of the patient. There's also an ID there. There is also a code that says whose ID is it, who assigned that number, 996756495 to it.

There is a box called record target that relates back to the document and says this is one of the people that were involved in this record. This happens to be the patient because it's the patient role, but presumably down below there is something else about the provider or the system that created this summary accordingly.

That notion of elements being within one another is kind of the fundamental access that we need to decide about because as an alternative we could, if you think of this as extended downward to where you got to the clinical data, we could have each element coded with the patient ID and the identity of the system that did it and the patient name or however else you want to identify the patient. Or we can assume this nesting occurs and that those relationships are not repeated dozens or hundreds of times, but are assumed by just the position of the different elements.

That's where the PCAST Report is challenging us. It's asking us to consider the possibility that repeating a lot of context information instead of assuming it from the structure has benefit in terms of the ability to apply very high end, large system techniques to the data.

Paul Egerman – Software Entrepreneur
Wes, excellent comments. One way –

Gary Marchionini – University of North Carolina – Dean & Professor
May I jump in; this is Gary; just to ask a question?

Paul Egerman – Software Entrepreneur
Sure.

Gary Marchionini – University of North Carolina – Dean & Professor
So assuming that there were privacy setting tags is it the intention that the privacy settings would be inherited to anything that was included within one of these groups? Because it seems to me that that's where some of the problems are going to come in if that's the case.

Paul Egerman – Software Entrepreneur
This is Paul. I guess my response to that is at least in Stage 1 the specification for this is not that granular. Privacy in Stage 1 is handled sort of like all or nothing.

Gary Marchionini – University of North Carolina – Dean & Professor
Okay.

Paul Egerman – Software Entrepreneur
And it's really kind of all or nothing. I expect at a document level in Stage 1 there is only one document, which is the continuity of care document. Is that right, Wes?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
We have to recognize that there are two related ways of handling data on the table and being discussed. The first is the entire document is viewed. As you pointed out, Paul, at the start of the call, this document is a summary. There has been an active process of picking out what is the relevant data and putting it in, some of which is done just by the definition of the document. Often it represents though a judgment by a clinician of what's relevant about this patient. In fact, the fact that he had an RFID chip implanted in his right triceps might not be relevant. In a less healthy patient where the amount of information begins to extend beyond what looks good on a PowerPoint slide there is a judgment that's made, but all of that together, this patient summary is related by the information necessary to summarize that patient at that point in time.

A lot of times, in a lot of systems when this data comes in it goes through a process that some people call shredding, which is misleading. What it means is that the individual problems, medications, allergies, labs and so forth are split off and stored as individual data in a database so that, for example, if I wanted to find all of the cholesterols for this patient at a dozen points in time over the last three years I could do that by just saying, "Retrieve all of the cholesterols," as opposed to, "Retrieve all of the documents. Examine all of the documents to see if they have cholesterol," and then pulling the cholesterol out. This is another area where we're being challenged to think about new technologies versus the old in terms of what's feasible in that regard.

The issue about assigning privacy to elements becomes apparent as you begin to look across documents at specific elements. So, for example, if someone had one AIDS test then; perhaps they were getting married; if someone has had one every month for the last three years then there is an inference that would be made about that patient. It is sometimes the class of data rather than the individual data element that people would like to protect.

Paul Egerman – Software Entrepreneur
Those are helpful comments, Wes. The observation that I wanted to make is in terms of Stage 1 of Meaningful Use and what's operational. The privacy, what's in the certification is there is no granular privacy. This is like the patient submitted –

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
There is no privacy in Stage 1 that I'm aware of.

Paul Egerman – Software Entrepreneur
Yes. That's right.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
There are data that individual implementations might use to create a privacy policy, but there's not even specific data that we think would be adequate to create a privacy –

Paul Egerman – Software Entrepreneur
Basically, various implementations are implementing through various concepts to this, but to the extent privacy preferences are applied to this, which they probably wouldn't be in this sort of emergency department use case, but they could be in other use cases, is in the context of Stage 1 right now. It's submit or don't submit.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Right and transition of care -

Paul Egerman – Software Entrepreneur
It's not going through this and saying, "Well, I'm okay with glaucoma, but I'm not okay with my Lyme Disease," or something.

Leslie Harris – Center for Democracy & Technology – President & CEO
This is Leslie. Can we separate out whether there's privacy from individual privacy preferences?

Paul Egerman – Software Entrepreneur
I think that's a great comment. So there are no privacy preferences –

Leslie Harris – Center for Democracy & Technology – President & CEO
Yes, I –

Paul Egerman – Software Entrepreneur
That's the best way to describe it, but what I wanted to do though, the main point; we maybe got lost a little bit in the details; the main point was I was trying to be helpful actually to your comment, respond to your comment, Leslie, to try to get a sense as to what's different, what is happening right now in Stage 1 of Meaningful Use and what's different for what is being proposed in PCAST.

Leslie Harris – Center for Democracy & Technology – President & CEO
Yes. That's very useful.

Paul Egerman – Software Entrepreneur
So the comments, to pick up again on Wes' comments, the idea is as you look at this summary in text form and realize there is a fair amount of computation involved and it's sort of like a package of data elements that are put together based on some assumptions that these are going to be reasonable data elements. So on the one hand it uses XML and tagged data elements, so it has that foundation. On the other hand it's sort of like this is what you always get. In other words, you get this kind of a summary; if you ask for it on this patient this is what you're going to get. So that's what I'm trying to do is to contrast where things are right now with what the PCAST Report is –

William Stead – Vanderbilt – Chief Strategy and Information Officer
This is Bill. Let me just highlight one more thing from Wes' comment. This summary that you get is, in fact, created by someone. That's another difference in that it's not an aggregation of information from all places independent of whether one person knows about it or thinks it's important or not. That's another, I think, relatively important distinction that will come out as we get into the other examples.

Paul Egerman – Software Entrepreneur
Sure. Bill, you're correct. It is created by someone. It's also another way to express my comments about the structure. There is also computation involved in creating this. In other words, this example shows body mass index. That's a formula. That's not actually a data element. It's created from other data elements. Even the labs; it's showing the most recent labs. It shows there is some element of calculation also in coming up with this document.

The other comment I'd give you about this document is that a ton of work has gone into it. In other words, there are a lot of very good people, who put a lot of effort into creating this concept. It is successful, but there's also the existence of this group of people, who've done such really good work, they're very proud of their work and so they're saying this has got to be the foundation. So we need to be aware that this exists.

What I wanted to try to do was to do my best to contrast that with what PCAST seems to be suggesting. Again, correct me when I don't quite do this right, but what I tried to do is with use case number two, was to take the same patient and just change the circumstances a little bit. A person goes to the emergency department after suffering some sort of a minor cut or something that occurred during a home improvement project in a bathroom. It turns out in this case only simple first aid is needed and because of the circumstances of the injury the ED nurse would like to check the status of the patient's tetanus immunization. So the contrast between this second use case and the first one, the first one was sort of a use case where a patient with severe chest pains is sort of trying to get that snapshot of what's going on with the patient's active meds, active problems. It seems to me that's probably what is needed in that clinical setting.

In this clinical setting though I tried to choose an example, which is more granular. There is only one data element that's really needed or requested, which is what is the status of the patient's tetanus immunization? The nurse wants to know, "Do I need to give another tetanus immunization?" The comment is in what exists with Meaningful Use Stage 1 you would still transmit that entire patient summary that we saw before.

Leslie Harris – Center for Democracy & Technology – President & CEO
This is Leslie. I have a question.

Paul Egerman – Software Entrepreneur
Sure.

Leslie Harris – Center for Democracy & Technology – President & CEO
I'm not a doctor. I don't play one on TV, but is that really all you need if the person has a bleeding disorder or an allergy to tetanus? I mean it's nice to say you only need one data element, but is that really true?

Steven Stack – St. Joseph Hospital East – Chair, ER Dept
This is Steve Stack. I am a doctor and I can finally say something on the call. I think that that's a level of detail that almost seems it may be technologically feasible, but it seems to me impractical. It seems to me that a regular CCD is just more pragmatic. To query a single data element seems a little, at this stage of the game, too precise and specific. So it would make more sense to me to build what the basic CCD would contain and the core set would at least include a problem list, a medication list and allergies at the minimum. If you wanted to put vaccinations in there that's fine. In certain settings that would be useful. I think the most recent or basic core set of laboratory, that that's also possible it could be useful. That core set you had there didn't include things like a creatinine for a renal function, which is really invaluable for certain people with chronic illness and stuff.

I think to go to the PCAST approach, as you've outlined it on this slide, and just ask for a single datum is a level of precision that I think is probably at a complexity that doesn't make much rational sense from the end user perspective as a clinician.

M
Paul, can I ask Steve a question?

Paul Egerman – Software Entrepreneur
Sure.

M
Steve, I think the first question is probably specific to the example, but is generalizable. How often in the ED setting do you really think I know everything I need to know except this one question. Second to that, is it important to you to know the context of the answer? For example, is it important to you to know whether the patient said they had a tetanus exam or you have an actual record of a provider who administered the tetanus vaccination?

Steven Stack – St. Joseph Hospital East – Chair, ER Dept
Using this use case right here, probably just because of the pace at which care is provided, unless this stuff was so fast and effortless we would ask the patient and if the patient said, "I've had one in five years," we'd be done and we'd trust them. If they said they didn't know or it wasn't done we'd probably just give it.

Now, of course, maybe life will be different in ten years and it will be so easy to get this information that we can begin not to repeat things we don't need to, but in the world I envision now, we would never query just to find the tetanus. You'd ask the patient and if they're uncertain you'd just give them a tetanus booster and they'd go, because you're not going to harm them by giving one extra tetanus booster.

Stephen Ondra – NeHC – Senior Policy Advisor
This is Steve Ondra speaking also as a doctor. I think what you're saying is true. It also defines to me what PCAST is trying to do, which is to not just deal with the current state, but how can we help that current state evolve into something more sophisticated. I can't count the times an ED is searching, there's a patient there, okay I know a lot about them. It's so frustrating to thumb through either an electronic or a paper record trying to find that one piece of data. If you have a system that can evolve into something that you can quickly query; I need to know this one little thing and I need to know it right now; that's a system that would immensely helpful and so I think if we look at what is practical today, also look at where we want to go as a health system electronically and we include what PCAST is looking at that's the pathway to that future in addition to addressing the needs today.

Paul Egerman – Software Entrepreneur
Yes. This is Paul. Let me sort of break into this conversation. I, as I said when I got started, what I said was sort of like a cartoon as to how it would all work. I don't know how realistic this is, but part of this conversation that we're having right now about do you want to look at the summary, do you want to look at a specific data element is, in effect, probably going to be a lot of what we hear when we do the hearing where a lot of people will say things like the summary and the collections of data is really what you want to look at. There is few examples where you want specific data elements. Other people will say something closer to what Steve is saying; yes there are some times when you want to be able to get the specific data element. Either way, if you look at the specific data element the thing that also is important to come to realize as we go through these use cases is this all has what I would call an operational impact. In other words, if you're going to go to an approach, as Steve Ondra just suggested or was trying to be suggested in this use case where you can look up a single data element, there has to be a methodology to do that. Right? The clinician has to do something to do that. So there is also an operational impact to it.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
But, Paul –

William Stead – Vanderbilt – Chief Strategy and Information Officer
This is Bill Stead. Let me try to clarify the cartoon a bit also in light of these comments, because what PCAST is saying is that we should be able to aggregate data in the smallest chunks it makes sense to exchange. They're not implying that a person would sit down and have to query for it item-by-item. They're implying there would be an application on the physician's desktop that would actually be able to query for the set of things that they needed in that context and that application could create something that looked like today's summary, just grabbing it from multiple places or it could in fact focus in on one item. So this, much as Wes said, with the other CDA when our cartoon is just a brief picture of what it looks like now; this is just trying to show one piece of what this thing is looking at, if that helps.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Bill, I'm having a little moment here. I hope I can share my aha. I think one of the things that follows directly in line with what you're saying is that some people look at the CDA and they say, "What's the difference? You can, if you've got a program, drill down into the CDA, across a bunch of CDAs and pull out the data you want. In fact, many programs do that in the process of accepting the CDA in the first place."

Others look at the CDA and they say, "Well, it's document oriented. It's the opposite of what we want in this particular sense of being able to get the granular data."

To a certain extent they're both right, because the CDA is used in multiple ways. Sometimes it's used to send granular data in a way that is organized by a document and sometimes it's used just to enclose a blob of text so that the lab data may be in there, but it may be in there in a form of what you could have seen on the screen if you were looking at a report rather than unstructured data.

I think we need to be clear that the granularity in the source data isn't a problem that is solved by one format or another. It's solved by the system that creates the source data. I would argue the fact that CDA supports both formats, actually enhances communication in an imperfect world.

Paul Egerman – Software Entrepreneur
Your comment, Wes, also is consistent with the PCAST Report that says the CDA approach or the clinical document architecture approach is a good foundation. So that's the observation. If I understood Bill's comment correctly about the source of the data is important because what I showed you in use case one; that clinical summary basically came form a single source and when I get to use case three we're going to talk about how you can do this with multiple sources.

Steven Stack – St. Joseph Hospital East – Chair, ER Dept
Paul?

Paul Egerman – Software Entrepreneur
Yes?

Steven Stack – St. Joseph Hospital East – Chair, ER Dept
It's Steve Stack. Just to Steve ... I think he raises a valid point and if this system can be designed in a way where you can have the option to select I think that that is useful. Back to, I think it was Leslie's question before, there are scenarios where you may only want a single data point, so if there was a menu that you could check or pick, just vaccinations or just medications or just allergies, there would be potential instances where you really only need to know one thing.

Paul Egerman – Software Entrepreneur
That's correct because it's also an issue about when you look at the PCAST Report at one point it says more atomic, which is not necessarily the same thing as atomic. So it's an interesting issue. When they proceed through this example relative to whether or not how atomic it is, the CCD action or there's something called a CCR, you can produce just the immunizations. The reason for showing this would be to say that's a little bit more granular than the first example where you have problems, medications, labs and immunizations. This just produces just immunizations. Maybe that's more atomic and maybe that is valuable; although, what I also tried to do was put forward sort of like a cartoon version of what I thought PCAST was saying really at an atomic level. So in this example this is what it would look like if you really were looking at a single data element, like the status of the tetanus shot.

What I think that PCAST is saying is for each data element you'd have these three things. You'd have something that would describe something about privacy. You'd have something that would describe attributes, privacy preferences. You'd have attributes of the data. The third thing is you'd have something called the provenance of the data. Then you'd actually have the data.

In this example the privacy preferences could say; and this is like just thrown completely out of the sky; something like yes to ED, yes to referring physicians. It says exceptions. Maybe it says no to Dr. James. Maybe it says no, I don't want this data element used in research.

The attributes would include things like the patient identification, perhaps the date, perhaps a vocabulary identification. In other words, it might take SNOMED CT or the actual number.

The provenance would include something like, say, the manufacturer of the immunization serum or whatever it is and the actual batch number that it came from. Maybe in provenance you would include other information about some audit trail history on the data element.

These are the kinds of concepts that are suggested, I think, by the PCAST Report.

Farzad Mostashari – ONC – Deputy National Coordinator for Programs & Policy
Paul, this is Farzad. Another item, which is, I don't think, explicitly discussed, but I think is quite important if we take data out of the document is the clinical context.

Paul Egerman – Software Entrepreneur
That's correct.

Farzad Mostashari – ONC – Deputy National Coordinator for Programs & Policy
So whether this medication was given in the context of a visit for headaches or in a visit for contraception; that I think and I think some of the comment that we received about what you lose when you move away from that view of the data is important to also consider how clinical context could be reflected as metadata as well.

Paul Egerman – Software Entrepreneur
Yes. That's a good comment, Farzad. That shows it's an interesting example that's used in the PCAST Report about mammograms, which I'm going to come to in my third use case, but there was an example of somebody doing research on mammograms. I think they were looking at the effectiveness of it as a screening tool or the effectiveness of certain ... factors as a screening tool. Sometimes mammograms are done as a diagnostic tool after a patient reports a specific problem, so that's some context as to why the test was ordered. Unless you know that I'm not sure that the results mean anything.

If I'm hearing you right, Farzad, one of the concerns that are expressed by this structure is you're not telling anything about the context of the particular data element when you report it this way.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
This is Wes. Again, I think that's a false dichotomy.

Paul Egerman – Software Entrepreneur
Okay.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I don't believe that; and this is just a belief; it's not something I can point to words, but I don't believe that the people who are proposing the PCAST Report are proposing that the context is lost in the process. They're proposing that it's available through the manipulation of the various kinds of metadata that's available.

Paul Egerman – Software Entrepreneur
Okay.

Farzad Mostashari – ONC – Deputy National Coordinator for Programs & Policy
I was just suggesting that that needs to be there –

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
The metadata?

Farzad Mostashari – ONC – Deputy National Coordinator for Programs & Policy
The metadata from which the context could be either explicitly noted or imputed.

Leslie Harris – Center for Democracy & Technology – President & CEO
This is Leslie. I think that's an optimistic view of the report. I hope you're right.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Well, let's face it; that in other work that's been done that has been the case, but I think, Paul, you really have put us onto one of the most important distinctions here, which is the combined look at this data in patient care and other use cases that want to use it for research. I would argue that whether you're using the great big PCAST in the sky or you're doing people with clipboards for collecting data, the issue of knowing whether you need information about the prior diagnosis of the patient is a part of the design of the study and that there are kinds of analyses that are more related towards hypothesis formulation than they are towards definitive conclusions, so that discovering a correlation between a medication and valve problems in the heart may be interesting to know until you recognize that this medication is used to treat valve problems in the heart. But nonetheless, it might show problems with specific analgesics or something like that, so there's a range of uses of data that might be accessible through the DEAS that we're being encouraged to balance one against the other.

Certainly, I would say if the proposal, when made concrete, said you couldn't drill down into that data and find out whether this patient had previously been treated for valve disease or other kinds of context information we talked about, then I would say that it's not even we're not allowed to evaluate the report, but I would say that we would want to chart a course that found a way to deal with that issue.

Paul Egerman – Software Entrepreneur
Okay. Those are helpful comments.

Richard Platt – Harvard Medical School – Professor & Chair
This is Richard Platt. On issues like this I think it would be extremely helpful if we could do a reasonably detailed work example of the kind of research that was just described.

M
Right.

Richard Platt – Harvard Medical School – Professor & Chair
I am having a very difficult time understanding how the approach described in the PCAST Report can really support a substantial range of the kind of research activities that I think would be high priority for many public uses.

Stan Huff – Intermountain Healthcare – Chief Medical Informatics Officer
Hello. This is Stan Huff. I apologize for not being here at first, but I think another use case that was in the same vein as ones we've been talking about is to extend this to think that the user of the data is actually a program rather than a care provider at a terminal.

We have lots of protocols that we're currently running. The one that comes to mind is the chronic anticoagulation management program and it would be a program that has a known set of characteristics, INRs and current Coumadin dose and other things that it uses to determine what to suggest next. I think that it just adds to what we've already said. It's not a single data point, but it's certainly a small subset of things that might be in a CCD document. It needs to do its job and so I think it's just adding to what's already been said; that there are things that besides care provider use cases, where you may be asking for a known, discreet subset of elements, to me the specific task, as opposed to assuming that it's a person who wants to know everything before they take a more broad range therapeutic, make a broad range therapeutic decision.

Paul Egerman – Software Entrepreneur
Those are helpful comments, although I think; I'm not sure; that what you just said, Stan, is a little bit different than what Richard Platt was talking about, because you're talking about an environment where there's – are you talking about like a decision support structure where a lot of data is used to help a physician make a clinical decision, like choose a dose or choose something –

Stan Huff – Intermountain Healthcare – Chief Medical Informatics Officer
Yes. It was different and –

Paul Egerman – Software Entrepreneur
Okay. That's different, because what Richard Platt is talking about –

Stan Huff – Intermountain Healthcare – Chief Medical Informatics Officer
He was talking about clinical trials –

Paul Egerman – Software Entrepreneur
Is some research analysis, so the context of like this example, somebody wanted to do some analysis of maybe surveillance on a particular manufacturer. They would look to see if some manufacturer had a higher incidence of something, of infections, compared to something else.

Richard Platt – Harvard Medical School – Professor & Chair
Just to be clear, I was talking about issues like the safety of medical products or like ... effectiveness research or like quality at large. Those are topics that are extremely high priority and that, as I understand the PCAST Report, will be extremely difficult to use the kind of methods that are most favored now.

Paul Egerman – Software Entrepreneur
Okay. Well, that's an issue that we've got to drill down on, so that's a good comment. Was somebody else trying to say something?

Carl Gunter – University of Illinois – Professor
Yes, Carl Gunter. I thought one thing to elaborate the slide here is the details that Bill Press gave as a presentation on the header, the metadata tagging headers. He proposed that they would be in three parts. I don't know if this is in the report directly; there would be a patient ID, which is some kind of collection of data in which the patient can be found. There would be a privacy tag and then there would be a clinical tag. I would reasonably predict the way we would do this is that the XML would have some kind of security headers that would include things like encryption information and digital signatures that would provide provenance of where the document came from. That's just a little elaboration on the slide here with the privacy as the headers.

Paul Egerman – Software Entrepreneur
And that may be. I mean this was our interpretation of what the PCAST Report said. We put down privacy preferences, attributes, which included patient ID, and provenance, but the clinical part, maybe that's the way you pick up what Farzad talked about in terms of –

Carl Gunter – University of Illinois – Professor
Provenance here probably means where this document came from.

Paul Egerman – Software Entrepreneur
This is a data element, where this data element came from.

Carl Gunter – University of Illinois – Professor
Well, who made this thing? What evidence? This is a valid piece of information.

Paul Egerman – Software Entrepreneur
That's correct. So the issue here though is in putting this forward it's not like I'm trying to make a proposal as to what it looks like. What I was trying to do is to sort of say these are the kinds of things that are suggested by the PCAST Report. ONC will have to do a lot of discussion about how they standardize, including identify it; the idea being that you have all of this information and then you've got this tagged data element and the difference between this and what you saw in the first use cases, again, was it's sort of like the independence of the data elements. That's the way I described it. In the first example everything is combined. It seems they're combined together. There are some structures. There are some definitions of what's involved and it does involve everything. Here is basically some sort of broader approach and each individual data element is tagged. That's what I was trying to produce as a contrast and trying to make it tangible. I don't know if that helped or not; maybe it made it worse.

Let me also move on to the third case. The third use case though was intended, I think, to bring up an issue I think Bill Stead mentioned earlier. In this example a patient changes providers. This is a variation of something that's in the report. The physician wishes to examine multiple mammograms taken at multiple sites over a period of time. So this is sort of like a different use case scenario. That is brought forward because this use case scenario cannot be done with the way Stage 1 of Meaningful Use is currently defined; first of all, because the CCD doesn't include any image. It doesn't include radiology. But it's also there is no query response process where you can say, "Give me all of this particular data element over a period of time."

The ONC staff did this sort of drawing of how this all works. It says the structure will still be privacy, attributes, provenance, data; although again, there is some question about specifically how that will work. The concept here though is you have an initiator. You have somebody who has a query, who could possibly query; it shows here; more than one DEAS system or database. The DEAS, this is why these things are hard to diagram; the DEAS does not really contain the data. It contains a pointer to a place where the data can be. So this example turns out each DEAS points to one site, but one of these could point to multiple sites. The idea though is that the initiator can do this inquiry and perhaps something like a Google search, but bring together data from multiple computer systems and sites in terms of sort of assembling it together and being able to view it together and possibly import it into their own EHR system.

That's something that's very different than what the first structure is. Let me pause there and see what people want to comment on.

Tim Elwell – Misys Open Source Solutions – Vice President
Paul, this is Tim Elwell. Just out of curiosity again, can you help me differentiate how the DEAS is different than, for instance, the FDS registry, right? When you're saying that you can't pull up images, I mean XDS does have a profile for images, XDSI. I mean again, I'm not trying to be argumentative here, but there is a registry component. There is the ability to tag data elements within that structure and you can query; they're queriable.

Paul Egerman – Software Entrepreneur
My impression, maybe I've got it wrong, Tim, is that Stage 1 of Meaningful Use for CCD did not include radiology.

Tim Elwell – Misys Open Source Solutions – Vice President
I'm not suggesting that Stage 1 does or doesn't, but in the CDA architecture it does have an XDSI profile.

Paul Egerman – Software Entrepreneur
Okay. So that's true. It may have that as the profile. I'm just trying to contrast what can be done right now in Stage 1 in Meaningful Use.

Tim Elwell – Misys Open Source Solutions – Vice President
We can tag today an XDSI registry if a patient has an identified study and it's registered in the XDS registry. We can pull that and collect that with any other CDA data associated with that particular patient. That's aggregated at the exchange.

Moreover, we can also do a query on particular tagged elements, normalize that through a semantic metathesaurus to identify where that information resides.

Paul Egerman – Software Entrepreneur
But what you're saying is what the technical capabilities of the architecture are, as opposed to what is in the current status, the Stage 1 of Meaningful Use, because we don't really have a query response.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Who is speaking there?

Paul Egerman – Software Entrepreneur
This is Paul Egerman.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
No, the other person.

Tim Elwell – Misys Open Source Solutions – Vice President
Tim Elwell, Wes.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Okay.

Farzad Mostashari – ONC – Deputy National Coordinator for Programs & Policy
This is Farzad. In terms of explicating PCAST for the rest of us, two questions came up for me with this diagram. The first was whether there is an ability to direct the query to particular DEASes given where that person's information is likely to reside. In other words, is there, A, a sufficiently small number of DEASes that it doesn't matter; B, some how technology just scales to be able to distribute queries to thousands, potentially, of DEASes; or C, some sort of central index of indices that lets you direct your query only to particular DEASes so that a distributed query could scale. That was my first question about that diagram.

My second question about the diagram was if a DEAS contains information for multiple providers the use case that you talked about included some knowledge of not just that this person's information is here, but potentially also in some of the use cases, information about the result I think, not just that there is a mammogram, but that there is a positive mammogram, for example.

I guess there's a question to explicate, I guess, let me sort of –

Paul Egerman – Software Entrepreneur
The question to explicate, on the first one my answer is that's a good question. I didn't understand that either from reading the report as to how you would know, how that would work, how you know whether it would be automatic, how you know whether to go to more than one DEAS. I don't know if anybody else –

Carl Gunter – University of Illinois – Professor
This is Carl Gunter. I took it; and I think they said this in the report; that they had at least partially in mind the kind of scalability that's been achieved by things like Google search. So you'll have a bunch of these things They're basically registries out there. Then you may have an entity that goes and corrals them and collects together to create a master index or it may be that it's more distributed than that.

But referring to this point about the registries, it seems like the DEAS is definitely a registry system, but it has other functions. For example, when you're doing the search there is the question of the privacy and metadata tags –

Paul Egerman – Software Entrepreneur
Right.

Carl Gunter – University of Illinois – Professor
That would determine what items are returned. Another function that it has is the key management for privacy purposes and this separation of concerns they propose.

Then another function that it would have is this global audit capability to allow you to see the system as a whole, as opposed to just local views at each of the participating institutions. So it's certainly a registry, but it's got a lot of other things it does too.

Paul Egerman – Software Entrepreneur
The key management, the way I understand it; tell me if I've got this right; is some how in the privacy preferences the way the security works is the initiator goes to the DEAS and some how everything is right and they're able to get the data. Then they could somewhat seamlessly then go to the EHR system that has the data. They don't have to like log in again and identify themselves again and go through a separate process that that the key management that somehow appears to initiate or just happen. Is that correct?

Carl Gunter – University of Illinois – Professor
I think an example might help with this one because I think that we have a little bit of guidance when we look at the architectures of Google Health and Microsoft HealthVault for the key infrastructure they use. The Microsoft HealthVault uses Azure, which keeps the files, but they don't trust Azure to do all of the privacy protection, so they have a key mechanism so that data is kept encrypted.

For example, if you give someone permission to see your file then they would need to go to the key authority and get the key. It would be done internally to Microsoft I assume, but the point is that you have this separation of concerns between a key authority, who never looks at medical data, and the medical data, which exists in the cloud, for example.

Paul Egerman – Software Entrepreneur
Okay. So, to get back to Farzad's two issues, one is how –

Farzad Mostashari – ONC – Deputy National Coordinator for Programs & Policy
Paul, I'm sorry. Maybe if I can just rephrase; my second part of the question was whether in some of the research use cases you essentially have to duplicate essentially all of the information at the source, at the index if you want to be able to do certain queries if that makes any sense. Is it essentially like Google; that CALs and caches is essentially a copy of all of the Web pages?

William Stead – Vanderbilt – Chief Strategy and Information Officer
This is Bill Stead. That's not what, at least as I read the report, they're quite explicit that that's not what they're talking about.

Farzad Mostashari – ONC – Deputy National Coordinator for Programs & Policy
I know, Bill, it's not. My question is how you can do a query that says I want to find the positive mammograms.

William Stead – Vanderbilt – Chief Strategy and Information Officer
I think the way that you would do that is first you would query the indexing service and it would tell you where there's information about that person. Again, as Stan said, this would be a program that was doing it, not the user. Then the program would then follow those links and it would pick the information that passed the privacy test up. If the metadata included semantic tags, which would vary by site if I read the report right, it would be able to narrow down what it wanted to pull back, but it would be narrowing it down from data at the site, not at the indexing level. Then it would pull back whatever wasn't narrowed out and then it would screen it down. I believe that's the sequence that it is intended to do.

Paul Egerman – Software Entrepreneur
Yes. Bill, this is Paul. What you said sounds right. I have to say as I read through the PCAST Report I was confused on this issue, but the way I read the report it was a lot of flexibility as to what was really going to be in terms of indexing on sort of like the left side, the DEAS side, versus what's on the right side, on the provider's side. So you could have, in sort of one extreme, simply on the DEAS side it's just a locator service. It just tells you which providers have any record on the patient. Then you have to go on to the provider's side to find more information about do they have a mammogram, do they have one that's positive. In other words, you might have to sort of, in effect, travel around to do that.

The sense I have from the report was that an indication to try not to have result information in the DEAS –

William Stead – Vanderbilt – Chief Strategy and Information Officer
This is Bill. You're absolutely correct, because what they're attempting to do is to actually decouple, separate the key management, the indexing, the storage of the information and the assembly of the information for viewing, for analysis. They're attempting to separate that to dramatically reduce the risk of it being put together and used wrong; and therefore, to minimize, to simplify the governance requirement.

Richard Platt – Harvard Medical School – Professor & Chair
It's Richard. Is this a fair place for me to ask a question of whether that basic approach is going to be capable of doing things like find all of the people, who have been under continuous observation for at least a year and have a first prescription of a specific medication? Is that a fair kind of question to ask ... picture and is this the right time to raise that question?

Paul Egerman – Software Entrepreneur
The answer is yes, it's a fair question to ask, but right now is not the time that I think we want to discuss it. I think we need to discuss it, perhaps, during the hearing and as we go forward, because if the issue is that this architecture doesn't do it then what we might want to do is point that out to ONC and perhaps point out alternatives or something that would accomplish the goal.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Paul, this is Dixie. That really is what Farzad was asking and my impression from the report was that they intended that kind of query, like how many people had a mammogram in the last year, to be the type of query that you would do on the research, the de-identified research database, not the DEAS.

Paul Egerman – Software Entrepreneur
Right. Yes.

Carl Gunter – University of Illinois – Professor
Carl Gunter here. One thing I was curious about in the report in looking at it was it seemed to me they had a missing concept of some kind of research aggregator that would use the DEAS to collect the data, perhaps, but would manage the research that was done on the data. So it might be that I think the report is just a high level thing and there may be important concepts missing that need to be added or elaborated.

Gary Marchionini – University of North Carolina – Dean & Professor
This is Gary. My understanding, as I read it, was that those DEASes would be those kinds of specialized indexes, if you will, that would be like in digital libraries people publish their metadata to a central repository. People query the repository and then go to the actual primary source to get the data.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences
Yes, that's my impression as well. Yes.

Gary Marchionini – University of North Carolina – Dean & Professor
Then any computation and aggregation and, presumably, interpretation would be done on the local side where the physician was trying to make a decision or do treatment, so there is this whole slew of queries and handoffs that are going to be taking place over the Internet to go out to a bunch of these repositories,

look up things, then go to the actual primary sources; send things back to the requester and trading those different kinds of indexing schemas, whether one is meant to deal with queries about conditions or pharmaceuticals and others with individuals, would all have their individual kinds of DEAS characteristics.

Paul Egerman – Software Entrepreneur
This is Paul. This is an interesting discussion and as the discussion indicates; and this is also what we saw, I think, in the public comment; there is a lot of questions about how this architecture is going to work. So, as it is described, I guess, in the PCAST Report as some very high level concepts that there are definitely a lot of questions.

But the issue I wanted to try to also bring out by showing you this sort of third use case is to sort of compare it against what right now is the current status of like Stage 1 of Meaningful Use where this kind of query process doesn't really exist within the EHR system, although there is and also we don't really have a way to sort of like assemble data from multiple locations, although we do have what's called HIE, health information exchange, organizations that are set up around the country mainly on state boundaries, but on large states more than one in a single state. Those organizations have various approaches to sort of like assembling data for multiple sources. Some of them have federated models where they just basically point to data. Others actually have more of a centralized model where the data is actually centralized in a single HIE or HIO and so they give some query capability to individual clinicians and there are a lot of hybrids that have a little bit of everything. The status of that though, that's why I described that; Hunt, if you're on the call, will hopefully correct me; as across the county uneven. There are some of these that are very far along and offer a lot of services and there are others though that are just in their very early stage of getting started.

Steven Stack – St. Joseph Hospital East – Chair, ER Dept
Hey, Paul? Paul?

Paul Egerman – Software Entrepreneur
Yes?

Steven Stack – St. Joseph Hospital East – Chair, ER Dept
This is Steve Stack. I can't help with this architectural stuff that we're talking about, but just using your use case three for when we get to the hearing, we seem to dodge in and out of different layers of this. I mean it's such a complex thing. Your use case three, from a clinical standpoint, most physicians, first of all, giving a radiology report is very different from getting the actual images.

Paul Egerman – Software Entrepreneur
Yes. I know.

Steven Stack – St. Joseph Hospital East – Chair, ER Dept
Every hospital I've worked at, and I've worked at quite a few in the last five years, has generally – I mean they don't generally, they all segregate their imaging data so the actual image is in a whole different storage system, separate from any kind of EMR or other data. I'm not saying that's the only way it's done, but that's the way it's been done at all of the places I've been. So 95% of doctors would only want the reports, not the images. Now, a surgeon may want the images or a specific specialist, but it's a whole different discussion. So the use case kind of blurs some things in its three-line simplicity.

The other thing is radiology reports, just using that example, are generally stored as text documents, not structured data elements, which makes that a whole other difficult thing. What I'm having a hard time grasping here is you guys all discussed how you can package the data and how you can make sure that it's going the right places and perhaps associate other metadata with it for its privacy settings or authorizations and things like that. I'm having a hard time following what data we are actually going to get and how it's going to be mixed and matched, because I think there is some borrowing that's going on.

Paul Egerman – Software Entrepreneur
Yes. Steve, this is Paul. Those are good comments. When we did this use case three we were actually reflecting the use case that's in the PCAST Report –

Steven Stack – St. Joseph Hospital East – Chair, ER Dept
Right.

Paul Egerman – Software Entrepreneur
So the PCAST Report, on page 51, talks about Dr. Jones and Dr. Jones does exactly this; assembles a list of locations where Abigail, the patient, has medical records and then attains the mammograms. The example is a bit challenging because, exactly as you said, it would be more likely that they'd be assembling the interpretations. There is, in radiology, mammograms is one place where there are more data elements or something called the bi-rad score, so they could be assembling the score on the mammograms that might be of interest. Your comment is certainly a valid one. I just did my best to take the example that was in the PCAST Report.

Steven Stack – St. Joseph Hospital East – Chair, ER Dept
Right.

Stan Huff – Intermountain Healthcare – Chief Medical Informatics Officer
Paul, this is Stan Huff. Getting back to your question about what PCAST might be proposing that's different, what peaked my thoughts were the idea that you mentioned briefly; that you might do the query and then they might actually store in their own system one or more of the images that they queried for. So the thought is, as I understand PCAST, they were thinking more of things staying distributed and that may be a distinction between what they're asking for and what we're doing now, what's envisioned in phase one. What happens in phase one is, for instance, that lab data or x-ray data or any kind of data is generated in a given system and then we use messaging, HL-7 messages or DICOM messages to move it into other systems and so the system retains copies of the data from the other sources or makes copies and then keeps them in your record from other sources.

It seemed PCAST had much more of flavor of indexing the data, leaving it where it is and asking for it from the source system rather than copying into the new system.

Paul Egerman – Software Entrepreneur
Exactly right. I mean if you contrast what you just said with what I said in that first use case example with the continuity of care document, the CCD, the way that's handled in Stage 1 of Meaningful Use is that entire, all of that data is generally in effect uploaded or imported into the EHR system as opposed to what PCAST seems to be implying; that you could do this inquiry and you could just gain access under some circumstances to the data where it exists. There are some challenges that people pointed out with that issue, but that is an important difference.

Stan Huff – Intermountain Healthcare – Chief Medical Informatics Officer
Yes and that's where I wanted to go just to make a comment or two. Again, that's very appealing to leave the data where it is because multiple copies of data usually cause trouble; in my life anyway they always have. But the challenge comes that even if that's technically feasible there are some medical legal reasons, for instance, and potentially performance reasons and this may be going past where we want to go in this discussion, but our attorneys basically are saying if you make a medical decision on data that is outside of our system we need a copy of that data. We can't trust that the source of that data will keep it and it will be available when we get sued 15 years from now.

Paul Egerman – Software Entrepreneur
Excellent comment.

M
I thought there was some vision of this in the report. You're drawing in encrypted data, which you can then view and then put back in encrypted form locally so that the data has some protection at rest, even though there are multiple copies of it was part of the vision that was expressed there.

Paul Egerman – Software Entrepreneur
That's right. Rather than necessarily dissect each of these issues, what my purpose in showing this material; I don't know whether or not we accomplished it; was to try to make some of this a little bit more tangible and to try to respond to what I think a few people had asked in the first call, which was to do our best to contrast what currently exists with what PCAST is suggesting. Indeed, as we talk about what currently exists we run into some challenges Ken and Wes and a few other pointed out, well, gee, the architecture that currently exists has some capabilities. That's certainly true, but I was trying to sort of say what's in Meaningful Use Stage 1. What does the criteria say that you have to do? That's the minimum thing that you have to do to qualify for the financial incentives. That was what I was comparing against the PCAST Report, not the capabilities of the architecture, where we are right now.

Leslie Harris – Center for Democracy & Technology – President & CEO
This is Leslie. I for one think it's very helpful and the fact that by setting up the use cases I think it just puts it in sharp relief the questions and that's what I was hoping would happen, so thank you.

Paul Egerman – Software Entrepreneur
Great. Even the second use case where there was a physician's question whether or not you would like a single data element, I think that's actually a very interesting discussion and Richard Platt's comments about the research, because the fact of the matter is when we put this stuff together we always, especially those of us who are not clinicians, we always tend to over simplify the reality of what goes on.

Leslie Harris – Center for Democracy & Technology – President & CEO
I admit to living with a clinician for almost 30 years, so –

Paul Egerman – Software Entrepreneur
Okay.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Paul, before we get too far I would like to suggest that we consider the agenda for testimony in light of the specific issue that Stan raised. I mean as the agenda stands now, it's possible that some institution may raise it, but I think it's worth creating some opportunity for someone to testify on sort of the specific legal-forensic issues associated with the PCAST proposal.

Paul Egerman – Software Entrepreneur
This is Paul. I think that's a great comment. It would be helpful if you had a specific suggestion for us.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
I'm going to ask the providers, Stan or the providers on to suggest someone –

Paul Egerman – Software Entrepreneur
If you could give some specific suggestion as to who might do that that would be helpful in terms of doing that. The reason I'm saying that, Wes, is it's just the time crunch of trying to get people organized –

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst
Yes. My suggestion would be to go to ..., but I bet you somebody on that call knows someone specific.

Paul Egerman – Software Entrepreneur
Yes. Maybe when we do the public comments people in the public could also, if you have comments in the public comment or can send an e-mail to Judy Sparrow with suggestions that would be helpful too.

But anyway, back to what we tried to accomplish with this was to make it a bit tangible. To get back to what Wes said, if you want to remind everybody about my comments; it may seem like they occurred like six days ago, but it was just a few hours ago, to e-mail your questions and suggested questions for the panelists and any suggestions for the people that are listed on your e-mail as TBD.

The other sort of loose end that we have that at some point we should have a discussion about was I send an e-mail out; I forget when; with an attempt to summarize the PCAST Report. So I put out an e-mail that I have like three major directions in the PCAST Report; accelerate progress, develop an architecture, have an evolutionary transition. Then I listed like six or seven architectural concepts, using extensible language, more atomic approaches. This was developed with Bill; Bill Stead and I put this together and it would be very helpful if people could review that. I'll send the e-mail out a gain and see if we could converge on the list of what we think are the basic concepts. One thing we've got to do is the baseline so that we understand what the PCAST Report says.

(Overlapping voices.)

W
I'm wondering if I can ask one thing that could probably be done in a one-page chart. I just want to make sure that everybody has a baseline understanding about what privacy protections exist now so that when we're looking at the recommendations from PCAST the people understand how different it is.

Paul Egerman – Software Entrepreneur
Okay.

W
I guess I got a little bit worried by there is no privacy now, so it may have been a ....

Carl Gunter – University of Illinois – Professor
I looked at your list. This is Carl. One thing I thought was that there should be more emphasis on the novelty of the DEAS and so I think in this call –

W
That too. Right.

Carl Gunter – University of Illinois – Professor
It seems like people have been focused mainly on the UEL, which I think has important novelty in it, but the DEAS is also a very novel thing –

W
As is the –

Carl Gunter – University of Illinois – Professor
If you could kind of break this into two parts; there is the data and the search. Those are the novel parts that need attention.

Paul Egerman – Software Entrepreneur
Okay. That's very helpful. What we'll try to do is our next meeting is on, if I got it right, February 10th and so we'll try to schedule some time for discussion. In the meantime, if people have comments like that, I want to encourage e-mail responses. I know Dixie sent out a response, which I appreciate, so that's a good way to have a conversation in the interim.

Looking at the clock, in a minute or two we've got to start the public comment phase, but let me first ask if people have any other questions? Are we heading in a good direction? If you have any questions in general, things that you would like us to be doing, any other comments? Bill Stead, do you have any comments?

William Stead – Vanderbilt – Chief Strategy and Information Officer
No, I'm good.

Paul Egerman – Software Entrepreneur
Farzad, do you have any comments? I think the silence means either he has no comments or he is on another workgroup call, one or the other.

So I think this has been a great call, but let's see if we have public comment.

Judy Sparrow – Office of the National Coordinator – Executive Director
Great. Thank you. Operator, can you please invite the public to make comments if anybody wishes to do so?

Operator
Yes. We do not have any comments at this time.

Judy Sparrow – Office of the National Coordinator – Executive Director
Okay. Thank you, operator. Paul and Bill, back to you.

Paul Egerman – Software Entrepreneur
So thank you very much for participating in our call. I'm looking forward to our call on February 10th and very much looking forward to our hearings on February 15th and February 16th. I also want to again thank the ONC staffing; Doug Fridsma, Jodi Daniel, Judy Sparrow, Farzad. Everybody is doing a terrific job and being stressed out to try to get things done in this schedule and to keep everything going, other things going that they have to do, so I wanted to especially thank the staff and thank you, all, very much for participating. Take care.

Judy Sparrow – Office of the National Coordinator – Executive Director
Thank you.

Public Comment Received During the Meeting

1. Data tagging ---- HL7/IHE/DICOM has confidentiality Code

2. DRM -- only works with a proprietary enforcement, that only supports central enforcement service

3. NOTE: There is a confidentiality Code ... yes this is existing standards and standards that are being used.

4. When will the preliminary agenda for the in person meeting be available?

5. Separate presentation (i.e. usability) from Interoperability (ie how data gets there)

6. Do NOT bind privacy-policy into the object it controls, you will end up with a fragile system where the object must always be changed when policy changes. -- systems engineering -- Why is the Policy committee working on systems engineering?

7. Use case #3 is exactly like the NHIN Exchange implementation of XDS. Why are they not even aware of what their own program (NHIN Exchange) has been doing?

8. Don't forget Medical Records retention regulations

9. Don't assume that the current infrastructure proposed for NHIN are broken. Please look at them closely before they are declared defective.